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Dealing with loss: Food and eating in women with ovarian cancer on parenteral nutrition

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TRANSPARENCY DECLARATION

The lead author affirms that this manuscript is an honest, accurate and transparent account of the study being reported. The lead author affirms that no important aspects of the study have been omitted and that any discrepancies from the study as planned have been explained.

CONFLICTS OF INTEREST AND AUTHORSHIP

None of the authors declare a conflict of interest. SB, SL, AC, LH and AMR obtained the funding and were involved in the initial conceptualisation of the study. AMS conducted the interviews. AMS and SB analysed the data. All authors interpreted the data. AMS wrote the original draft of the paper. All authors reviewed, revised and edited the paper. All authors read and approved the final manuscript.

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ABSTRACT

Background

Malignant bowel obstruction is a common complication of ovarian cancer, resulting in limited oral intake. Home parenteral nutrition (HPN) may be offered to patients in this condition to meet nutritional requirements. However, it is not known how they experience being unable to eat. This study reports how patients related to food whilst receiving HPN.

Methods

A qualitative study underpinned by phenomenology with women with advanced ovarian cancer in bowel obstruction receiving parenteral nutrition. Interview transcripts were analysed thematically guided by the techniques of Van Manen.

Results

We recruited 20 women to the study. Participants were interviewed a maximum of four times and a total of 39 in-depth longitudinal interviews were conducted.

Participants could tolerate minimal amounts of food, if they had a venting gastrostomy. Not being able to eat engendered a sense of sadness and loss, and most women found it challenging to be in the presence of others eating. They adopted strategies to cope, which included fantasising about food and watching cookery programmes. These approaches were not a long term solution either participants came to terms with their loss or the strategies became less effective in providing relief.

Conclusion

HPN meets the nutritional requirements of patients with malignant bowel obstruction, but cannot replace the non-nutritive functions of food. Healthcare professionals can offer a patient centred approach by acknowledging the difficulties patients may face and wherever possible encourage them to focus on the positive benefits of interacting with people rather than the loss of eating on social occasions.

INTRODUCTION

Ovarian cancer is the sixth most prevalent cancer in the UK in women and most are diagnosed at an advanced stage^(1, 2). Malignant bowel obstruction (MBO) is a common complication of advanced ovarian cancer occurring in between 20 to 50% of patients⁽³⁻⁶⁾. Patients with this condition are not able to eat normally. They may be fitted with a venting gastrostomy to enable them to have small amounts of soft food and fluids for taste and comfort. In addition, they may be treated with home parenteral nutrition (HPN)⁽⁷⁾.

HPN is used in patients with intestinal insufficiency both from benign and cancerous causes. Although, HPN has been found to be a safe and efficient procedure, it does carry risks of complications such as line infections⁽⁸⁾. The benefit of HPN is that it can be administered outside of hospital allowing patients to be in their own environment. Although median survival lengths quoted in the literature vary from as little as 15 days for patients with cancer and palliative needs, it can be for substantial periods of time⁽⁹⁾. Some studies have reported these patients surviving on average more than 200 days on HPN⁽¹⁰⁾. Artificial feeding means that patients' nutritional and hydration requirements can be met and for patients with MBO it is replacing food that they cannot eat.

Food, however, is not only a means of delivering nutrition. Food provides rhythm and structure to days, weeks, months and seasons⁽¹¹⁾. As well as punctuating the ordinary, food is key in special occasions, which are often focused around celebratory meals. It can be perceived involvement in the social experience includes being able to eat a shared meal. In addition, food can play a fundamental role in quality of life as the act of eating in itself provides enjoyment⁽¹²⁾. Therefore, as well as its nutritive function, food is invested with social, emotional and cultural meaning⁽¹³⁾.

Patients in MBO are unable to eat normally for an extended period of time and the non-nutritive functions of food are denied to them. Little is known how these patients feel and behave around food, whilst receiving artificial feeding as previous research has focused on supplementary HPN which has added to oral intake not replaced it completely^(14, 15). However, the numbers of patients in MBO receiving HPN are increasing as people with advanced cancer on HPN increase and healthcare professionals need to be able to support

these patients throughout this time ⁽¹⁶⁾. The aim of this study is to report patients' experiences of losing the non-nutritive aspects of food over a protracted period of time.

METHODS

The study is part of a larger project investigating HPN in women with ovarian cancer, which involved interviewing patients, relatives and healthcare professionals ^(9, 17-20) this report focusses on patients' relationship with food whilst being on parenteral nutrition. Participants had advanced ovarian cancer (\geq stage III) and were admitted to an oncology hospital with inoperable malignant bowel obstruction between October 2016 and December 2017. They were introduced to the study by an oncologist or dietitian and all gave written informed consent. The study was approved by East of England Cambridge Central Research Ethics Committee on behalf of the Health Research Authority National Research Ethics Service.

Data collection

The aim was to interview patients up to four times; once in hospital and up to three times at home, . A topic guide was used to structure the interview, but was employed flexibly so that the interviewer (a university based researcher, who was not a member of the multidisciplinary team) could investigate topics raised by the interviewee (see supplementary material1). With participant permission, all interviews were audio-recorded and encrypted at source; interviews lasted up to one hour.

Data analysis

Nvivo 11 (QSR International Pty Ltd, Doncaster, VIC, Australia) was used to manage the interviews. Transcripts were analysed using the techniques of Van Manen⁽²¹⁾. Initially, the transcript was read to gain an understanding of the interview as a whole, particularly regarding the patients' feelings regarding food and eating whilst receiving HPN. The analysis then moved on to a detailed line by line coding. Themes were formulated from reflection on the codes, with similar ideas being grouped together to highlight the essence of the

experience of having a restricted intake whilst on HPN. Particular attention was given to how patient's experience in relation to food and eating evolved over time.

Rigour was introduced by having two authors (AMS and SB) discuss and agree the coding framework. The interviewer (AMS) kept field notes and a reflective diary during the process of data collection and analysis. The longitudinal nature of the interviews allowed an opportunity for participants to reflect on previous interviews. This meant that changes in attitude that patients had to food and eating could be documented over time.

Quotations have been used to illustrate the themes. All names are pseudonyms and the ages of patients at the first interviews are given.

RESULTS

HPN was considered with 26 patients and all were invited to participate in the study, of these 20 patients agreed to be interviewed. The intention was that patients would be interviewed four times, however there was attrition at each stage due to patients dying or becoming too unwell to take part. In total 39 interviews were conducted; with 20 patients interviewed initially, 9 were interviewed twice, 7 three times and 3 participated in a fourth interview. Four patients were not discharged on HPN. One was discharged to hospice care, another decided to go home without HPN and two were assessed as unsuitable by the medical team.

Median survival for patients was 156 days (range 46 to 156 days) measured from admission with bowel obstruction.

Four themes were identified moving from what the participants were eating, to how patients felt being in the context of food and not being able to eat normally and the strategies they employed to deal with the loss of eating (see supplementary material 2 for further quotations).

Patients' oral intake

Participants discussed what they were taking orally and most ate very little. Some patients would take a forkful of food from other people plates: "*If anybody is eating something... I just pick*" (Charlotte, 60), sometimes chewing food and spitting it out "*I've had pineapple and spit*

it back out. Just so long as I get the flavour”: (Sally, 63). However, others were fearful of the venting gastrostomy tube becoming blocked.

One woman was so concerned about this she limited herself to food that would melt in her mouth, even though she missed food terribly and did not like what she was eating.

Katherine: I'm making sure I go for stuff that's going to melt type of thing. I mean, I can have a bit of chocolate, you know.

Interviewer: But do you like chocolate?

Katherine: No, but I do try a bit now and again (Katherine, 56)

Others did not have anything more than sips of fluid and for one patient this was all she could have as it was not possible to fit a venting gastrostomy.

In contrast, one patient reported she was eating small varied meals: cod in parsley sauce, casserole and mash. However, she had on-going problems with nausea and vomiting, and at one point her venting gastrostomy tube blocked necessitating an in-patient stay for replacement. She had been told by healthcare professionals not to eat so much to alleviate her vomiting, but she did not seem to take this on-board. It was only when she had been on HPN for around six months she stopped eating, having only juice to drink and occasionally sucking on the segment of a tangerine. Her nausea and vomiting subsided and she became much stronger. She then commented that she had “*just very, very little [sickness]. And I can go days [without being sick]*” (Maureen, 72).

Being in the context of food

In general participants found being in the vicinity of food challenging, and mealtimes in hospital were particularly difficult. There was no escape from people eating around them; if they stayed in bed or if they went to the day room they would encounter other patients eating. The impact was exaggerated by a protected mealtime policy that required anyone who was not based on the ward or serving food to leave. Thus the whole focus of everyone on the ward

was on meals. Patients dealt with this situation differently, using various distraction techniques: One woman closed her eyes: *"I had to shut my eyes while they were eating their lunches...but I could still hear the knives and forks clinking thinking, oh, hurry up and finish"* (Susan, 73). Another woman distracted herself with a book and another somewhat surprisingly looked at recipes on the internet.

Interviewer: How do you feel when everybody else is eating around you?

Louise: It's extremely frustrating, but there's not a lot you can do, is there, it's not their fault, is it? They've got to eat to get better. It's torture...

Interviewer: And do you do anything to [deal with] that?

Louise: I tend to look at recipes on the internet (Louise, 57)

Other patients used humour to get them through: *"I just say, [to other patients] oh go on and feed your...fat face. I suppose you're having a packet of Hula Hoops now. You know, just make a joke of it"* (Sally, 63)

When at home some women could not tolerate people eating in front of them. So, relatives would eat in another room if there was space in the house: *"B. has his meals in the kitchen so I don't go in there while he's [eating]"* (Susan, 73). One woman's house was small with only two rooms downstairs so the only place for her husband to sit down and eat his meals was in the lounge besides her, which she found difficult. Other women were less disturbed by others eating around them, with one occasionally cooking for her husband: *"He's had a full cooked breakfast I did this morning"* (Sally, 63). Her husband, however, felt guilty eating around his wife:

He didn't feel comfortable eating it while I couldn't eat....Sitting at a table and you think...look at her sitting in that room can't have [anything] and look at me shovelling all this in...it's mental strain on him...He's lost a bit of weight (Sally, 63)

Women could feel differently about being in the presence of others eating, depending on the function that food was playing at the particular time. One woman who did not mind if her daughter ate a sandwich when she visited, did not want to be at the table at Christmas time. Rather than join in with the conversation, she preferred to sit separately with her back to the table:

I'll be going [to daughter's house] on Christmas Day for a few hours. It's not easy because I can't eat, but I'll have a little glass of champagne or something like that...But I won't have a plate. I said [to daughter], don't please put me at the table. ...she's got a nice comfortable sofa there, so I'll have a drink...And the living room is actually facing the back garden, which is quite nice to look out (Maureen, 72)

Sense of loss

The loss of being able to eat was profound for the patients: *'I just miss food. Yeah, you find yourself dreaming about daft things, you know, bits of food, ooh I fancy that'* (Charlotte, 60). The women realised that they were receiving all the nutrition they needed from the HPN, but they expressed an emotional loss, as eating is associated with normality. One patient who retained the hope that she might return to eating commented: *"I mean I know I'm getting my vitamins and everything, but it's the actual food going in your stomach...it's just wanting to get back to normal, if you see what I mean, whatever normal is these days"* (Katherine, 56). This patient felt: *"like an empty shell"* (Katherine, 56) as she did not have food inside of her to fight the cancer.

Eating is an important part of daily living, which is enjoyed almost without thinking and the women voiced sadness that this had been taken away from them:

"I'm not hungry, I don't feel hungry and yet when I see it I'm thinking but I...I don't say it sometimes because they're just sitting there and eating, normally, not even having to think about it. I thought I'll never eat anything." (Susan, 73)

This lack of normality made the women feel isolated: *"It really annoys me that I can't join in things"* (Louise, 57). They felt excluded from the activity of eating but also socially isolated

as it was difficult for others to understand their situation: *“you can’t expect anybody to understand who’s not got to do it. It’s like one of them things, unless you’ve done it you don’t fully understand”* (Katherine, 56).

As well as being a loss for the patients it was also a loss for their families. One woman who found it problematic to be around food was sad about the impact that this had on her family who she perceived had lost their traditional way of celebrating Christmas, as they had arranged an alternative Christmas dinner without the patient present: *“They are not even cooking a Christmas dinner....And that upsets me for them”* (Bella, 70)

Strategies to cope with loss

Women used different strategies to cope with this loss; some as might be predicted, sought to avoid food and eating as much as possible. A number of them took the surprising step of looking at recipes, as mentioned above, or watching cookery programmes. Others would fantasise about food, thinking about different foods for the appropriate time of day, or about meals they had previously enjoyed whilst on holiday when receiving the HPN: *“I’ve a vivid imagination so Sunday breakfast is scrambled egg and smoked salmon and my roast at lunchtime.”* (Melissa, 69)

It was interesting to see how the strategies adopted evolved over time; following discharge home, one patient started watching cookery programmes and would think what the food tasted like when the presenters tasted the food at the end: *“I like watching [cookery programmes] because I think, when it’s going in I think, oh their tasting that then...I think, look at that going in now, they’re tasting that bacon”* (Katherine, 56). At her next interview, she was still watching cookery programmes but she reported: *“I’m looking at stuff and I thought well I can’t really remember what it tastes like anymore”* (Katherine, 56). By her final interview, she found watching such programmes difficult:

I did watch MasterChef...last night...when they plate it all up and then they're cutting it and they're eating, it's when it goes in their mouth that annoys me. It's not too bad watching them cook it, but it's when...they start eating it, I just think, look at that. Because I think back to what I liked...I think, oh, I used to love that. (Katherine, 56)

The patient who looked up recipes on line whilst she was in the hospital, watched cookery programmes at home. However, during a follow up interview she commented she was finding it challenging to watch them. *"I do [watch cookery programmes]. I always have done, anyway, because I do like my food. And I do cook. So, it's a bit of torture, really"* (Louise, 57). By her third interview, she was avoiding watching them. The reminder of her losses was too much for her that she could not eat and if the programme was set in another country that she could no longer travel far and go on holiday.

Well I used to watch all the cooking programmes so I'm definitely avoiding them now... It upsets me sometimes so I'm best off not watching them... Gino D'Acampo's on next week... I'm not watching them... That'll be like a double kick in the stomach 'cause he's going around the Italian coast cooking. What can I say? I'm never going to get there now (Louise, 57)

Another patient illustrated a different experience than the other two patients discussed above. At first she thought about meals on holiday whilst receiving HPN.

What I do, I pretend when it goes on my feed, I say, I'm starting my soup... I imagine it.... I've had lobster thermidor... I think about the holidays we've been on, and restaurants that we've been to (Pearl, 72)

She became less interested in doing this for herself as time progressed. However, the nurses who administered the HPN and her husband started to ask her what she was having.

Pearl: Oh, and one of the nurses asked me, she said, what are you having tonight, Pearl? I said, well, my big fillet's steak here in peppercorn sauce definitely.... And I used to make light of it like that, it's just I'm not really missing it.

Interviewer: So it doesn't sound to me like food is a big miss in your life, is that right or not right?

Pearl: I think it was in the beginning but it's not now, no (Pearl, 72)

She said that she would think of something to try to make her husband and the nurses laugh. So, it seemed like she was at that point doing it for others. She hosted a family party enjoying people's company and was unconcerned about being around food, even ensuring everyone's favourite food was provided:

I want to have all the family around for lunch...my sister in law [said] can we have those prawns that we had at Christmas...I said you can definitely have them...we're hoping it'll be at the end of this month so that everybody can get together and just a laugh, that's what I like, conversation and laughing, yeah, I like that (Pearl, 72)

DISCUSSION

This is the first study to interview patients with MBO receiving HPN longitudinally so that it was possible to track patients' responses to not being able to eat over time. They found losing the non-nutritive aspects of food difficult and some found it challenging to be in the presence of other people eating. This invoked a sense of loss in patients and various strategies were used to overcome these feelings, such as watching cookery programmes or fantasising about food. For some their sense of loss dissipated over time, but this was not the case for all.

Previous research focused on patients' experience of food and eating where HPN is supplementary to oral nutrition ^(14, 15). One study investigated patients with benign intestinal failure and found food and eating remained an important facet of quality of life ⁽¹⁵⁾. Although patient's eating was circumscribed by their illness, they were still able to join in the social aspect of eating, such as going out to restaurants and celebratory meals. Another study focused on patients with advanced cancer, who did not have MBO ⁽¹⁴⁾. For these patients, HPN meant that mealtimes became less pressured and more enjoyable as they could eat what appealed to them rather than focusing on meeting their nutritional requirements. This can be contrasted with the women interviewed in this study where the social aspect of eating with others was denied to them and they felt isolated.

Although, the method of artificial feeding differs, the findings of our study more closely mirrored those of Walker *et al*⁽²²⁾. These researchers analysed open ended survey questions of patients fitted with percutaneous endoscopic gastrostomy (PEG) feeding tubes who had minimal oral intake. Like the participants in our study, the patients with a PEG experienced being unable to eat a social loss as they were could not participate in social situations that involved eating, particularly around special occasions. Walker *et al.* concurs with our findings and other research that patients not being able to eat had an impact on family members who avoided eating in front of them^(22, 23). Food and mealtimes, rather than acting as a social glue in relationships, became a point of separation and isolation as family members ate in different rooms.

There were a plethora of ways that patients dealt with the losses they faced. Some took to fantasising about food, a technique also used by patients with head and neck cancer about foods who could no longer eat ⁽²⁴⁾. Other patients avoided social situations involving food. Some did this whilst continuing to watch cookery programmes, which might seem a counterintuitive way of dealing with the loss of eating. However, it addresses the social isolation that being unable to eat causes. Patients could interact with food in the same way as everyone else – watching food being prepared and eaten, but unable to taste it themselves.

These strategies were only effective in the short term. For two of the patients watching cookery programmes became less successful as time progressed. Eventually this tactic seemed to heighten their sense of loss rather than provide a release or outlet as it had done previously.

Strategies such as fantasising about food were also dropped as they were no longer necessary to deal the loss as patients moved beyond having problems being around food. For one patient in this study, the emotional loss of not being able to eat seemed to dissipate. It could be that some reached what Kubler-Ross and others have described as a sense of acceptance⁽²⁵⁻²⁷⁾; where the person comes to a sense of peace about what has been lost and accepts the situation.

This study focused on HPN in ovarian cancer patients, which whilst giving a comprehensive insight into how this group of patients felt about the loss of eating over time could be seen as one of its limitations; as the patients had ovarian cancer, all the participants were women. It may be men in this situation would cope differently to the women in this study. Also as with all qualitative research the sample size was small and there was a drop off of participants at each stage due to the nature of the disease . However, given the longitudinal in-depth methodology with some patients undertaking four interviews it is likely that the results would resonate with patients in similar contexts.

Dietitians dealing with patients with cancer or starting them on parenteral nutrition are appropriately focused on ensuring patient's nutritional requirements are met⁽²⁸⁾. However, when dealing with patients who will not recover the ability to eat, it is important that they also keep in mind the symbolic and social nature of food as well as its nutritive function. Healthcare professionals can offer a patient centred approach, by using good communication skills; listening to patients and acknowledging the problems they may face ⁽²⁹⁾. Also wherever possible they could encourage them and to focus on the positive benefits of being with family and friends in social situations rather than the food they cannot eat.

Conclusion

Parenteral nutrition is the only method of providing nutrition to patients with malignant bowel obstruction. However, it cannot replace the non-nutritive aspects of food and some patients are more successful to adapting to this loss than others. Healthcare professionals need to be aware of this and offer appropriate patient centred support.

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